Improving Care for Seriously and Terminally Ill Patients

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Overview

- Chronic serious illness: our new reality
- The value equation: quality and cost in our new reality
- Improving systems of care through integration of palliative care

Global Aging

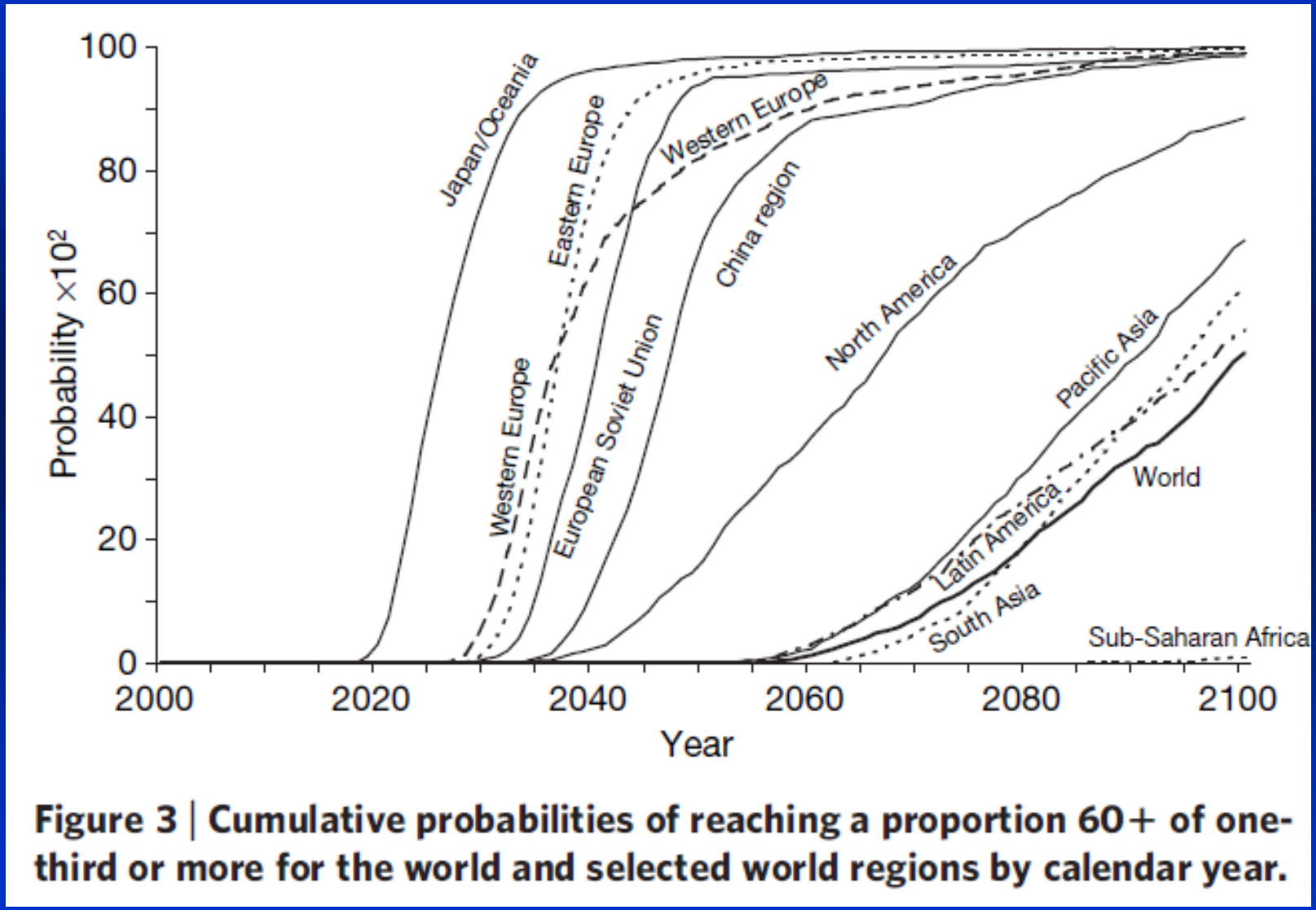
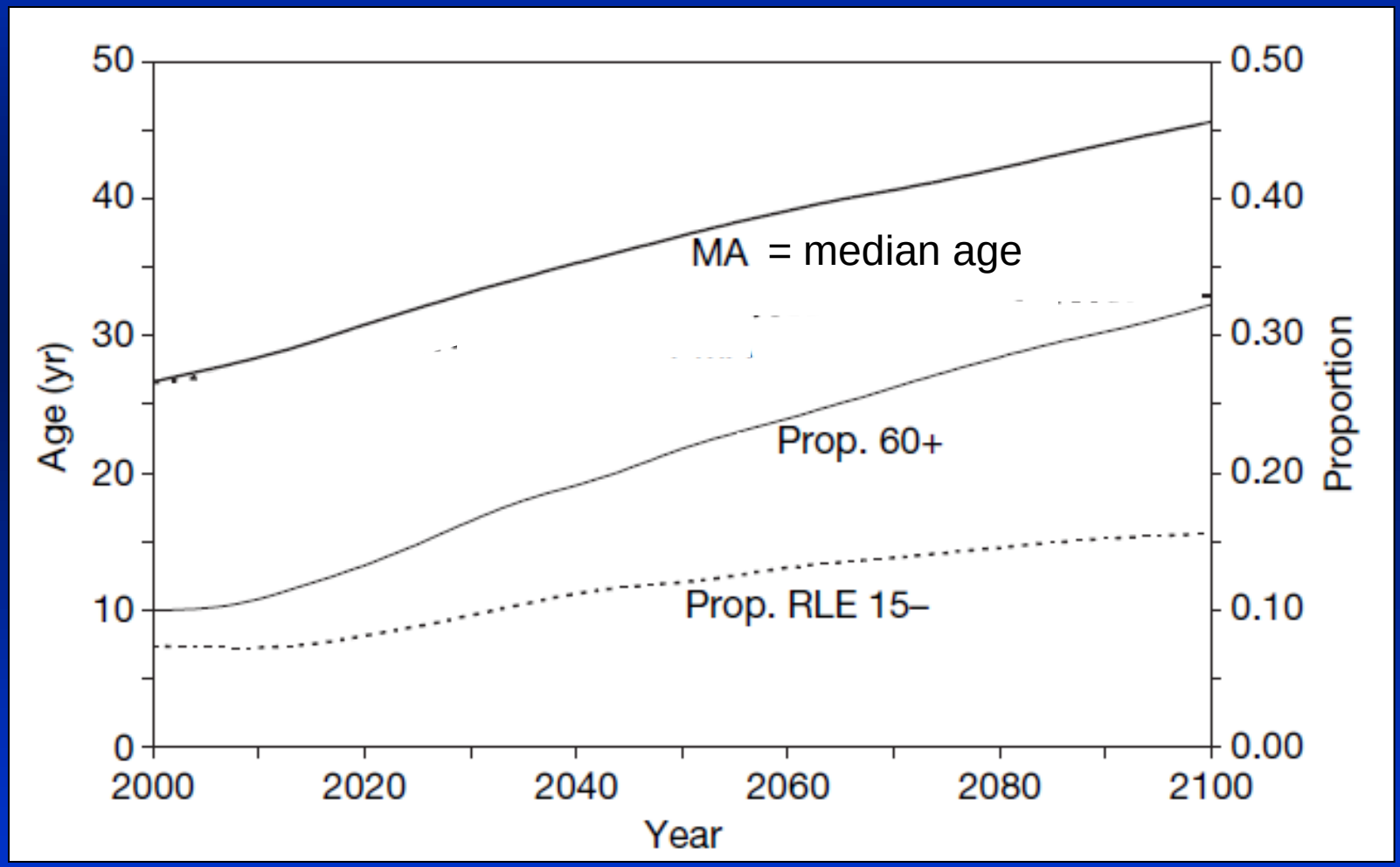


Figure 3 | Cumulative probabilities of reaching a proportion 60+ of one-third or more for the world and selected world regions by calendar year.

Lutz et al. Nature, 2008

Global Aging



RLE=Remaining Life Expectancy

Lutz et al. Nature, 2008

Global Aging and the Snake who ate the Rat

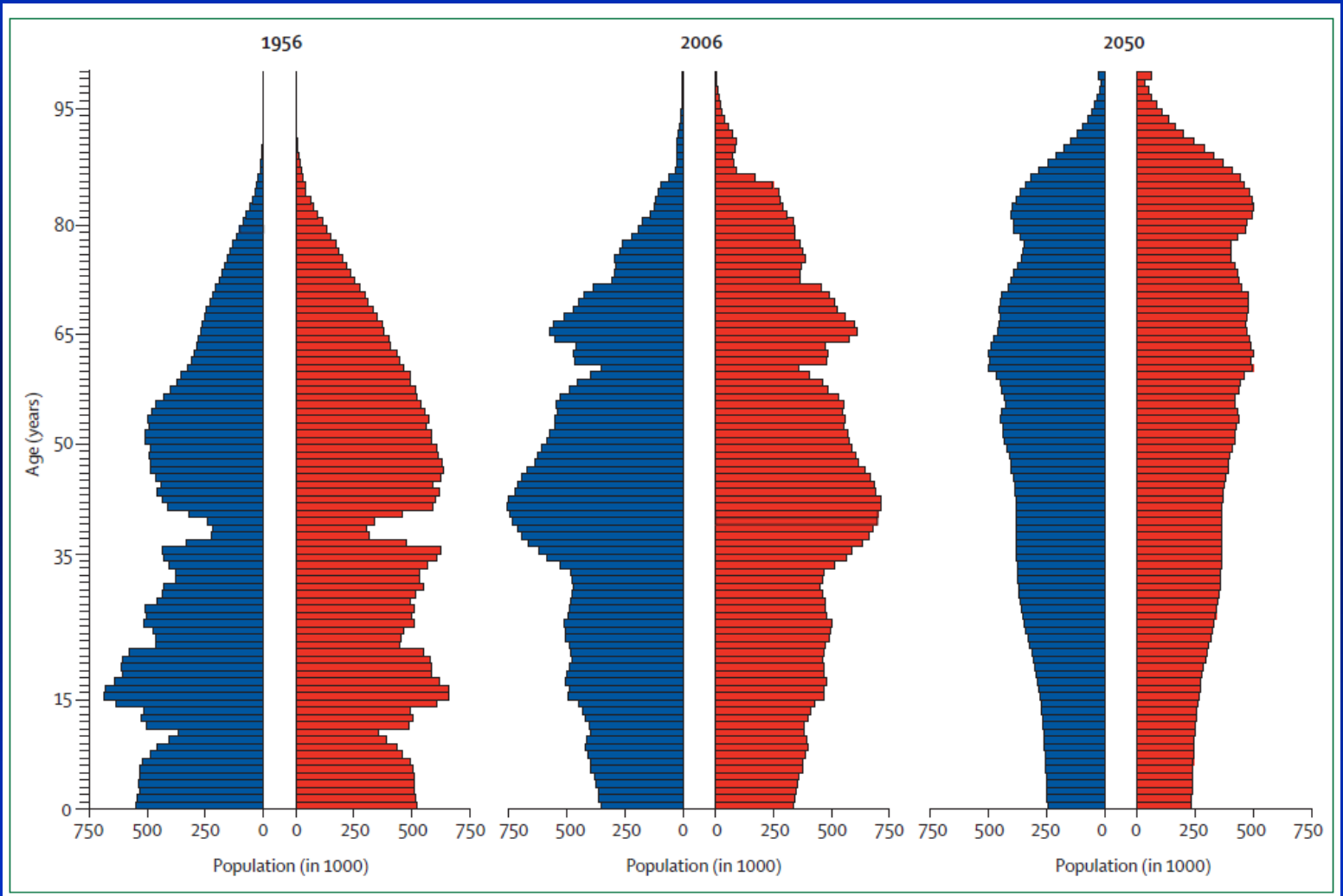
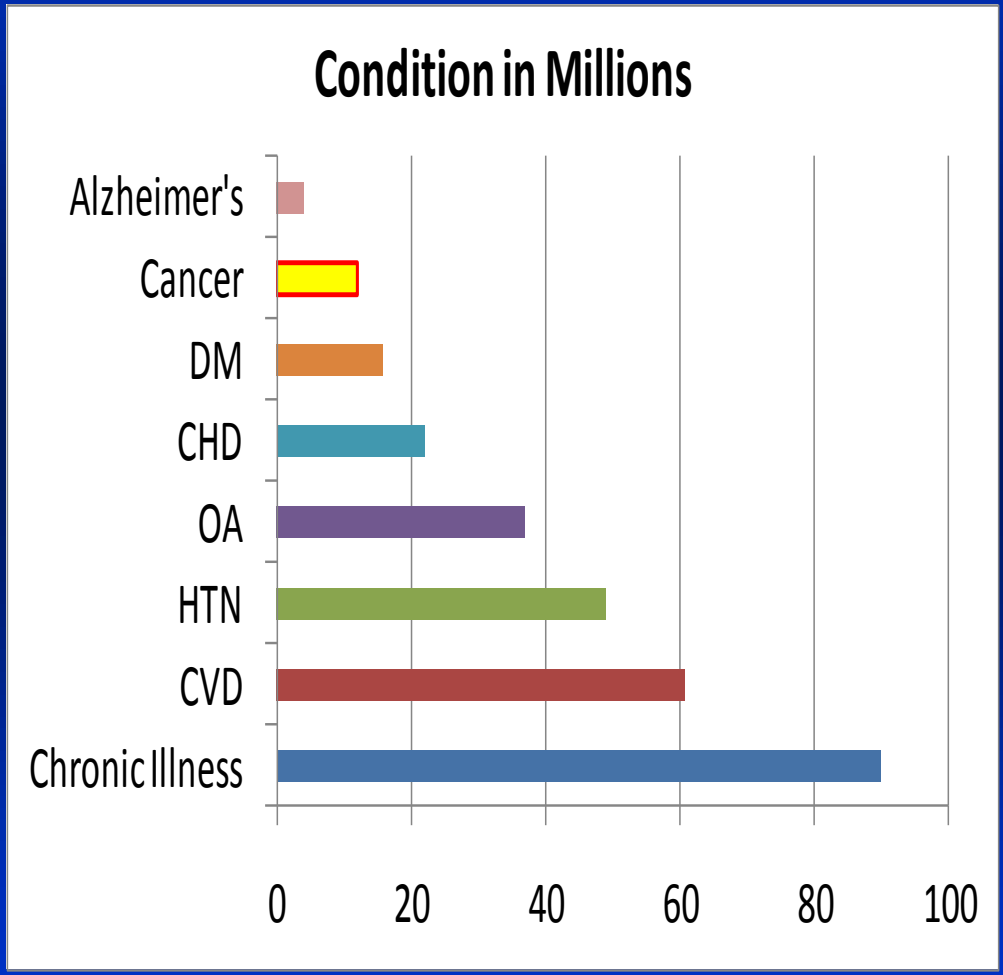


Figure 3: Population pyramids for Germany in 1956, 2006, and 2050

Christenson et al. Lancet 2008

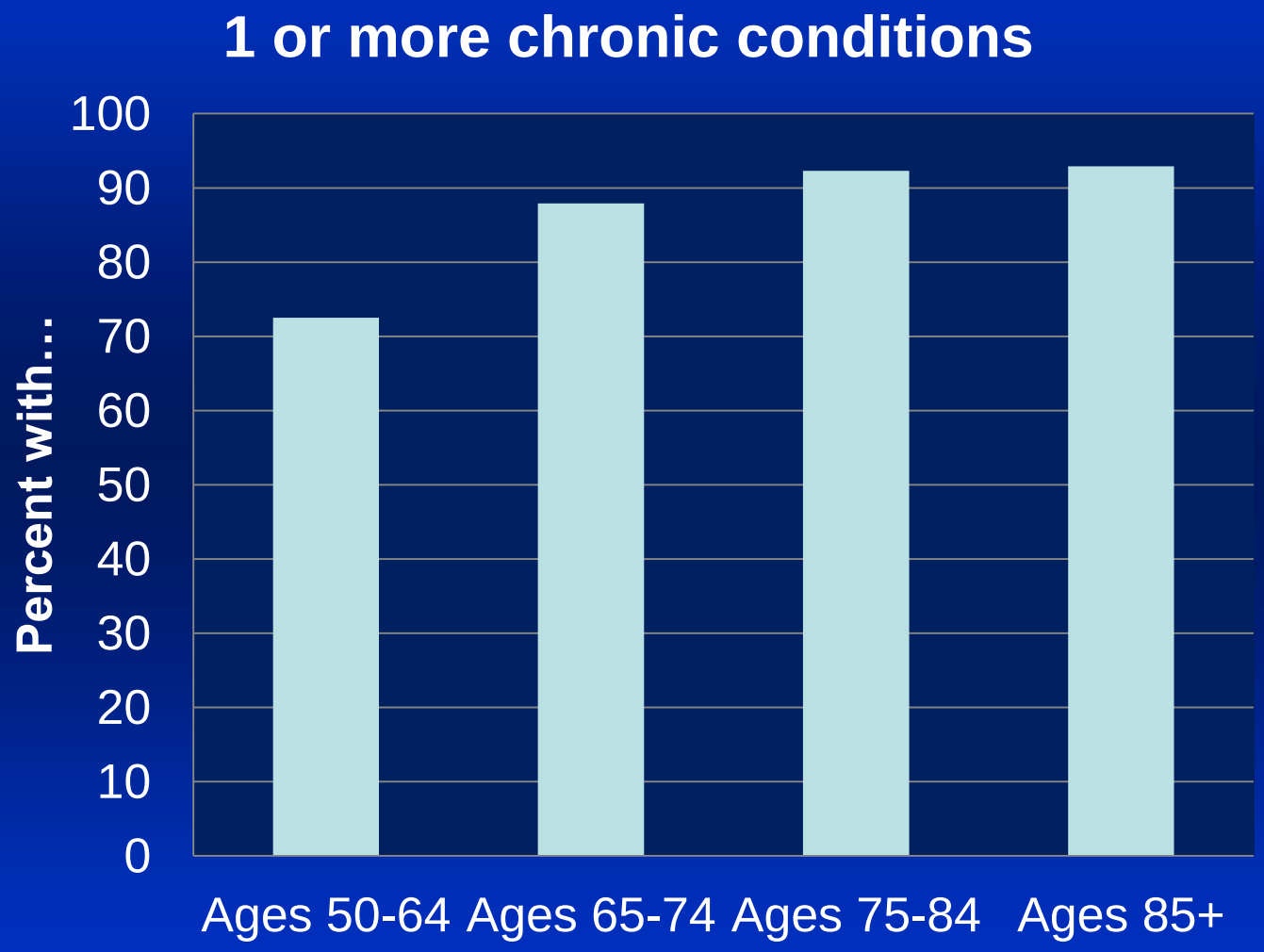
The Crisis of Chronic Illness



Disease	Prevalence Estimate
Chronic Illness	1 in 3
CVD	1 in 4
HTN	1 in 5
Arthritis	1 in 7
Osteoporosis	1 in 9
DM	1 in 12
CHD	1 in 17
COPD	1 in 20
Kidney Disease	1 in 26
Cancer	1 in 30
Alzheimer's	1 in 68

Source: Centers for Disease Control; NHLBI, NIAMS

Chronic Illness and Aging



Johns Hopkins Bloomberg School of Public Health analysis
Of MEPS, 2005 (Does not include people in institutions)

Chronic Serious Illness

- Longer survival with advanced disease
- High illness and symptom burden
- Management complexity increased
  - Patient/caregiver fatigue
  - Ongoing financial stressors from serious illness
  - Multiple providers
  - Dynamic goals and treatment preferences
  - Conflicting/interacting treatment regimens

Serious Chronic Illnesses in Older Adults: Some examples

- Chronic dialysis
  - 95% of those with chronic kidney disease are over 65 years of age (5.9 million)
  - Geriatric population most rapidly growing kidney failure population in the U.S.
  - In 2008, 80,000 adults 75 years and older received dialysis

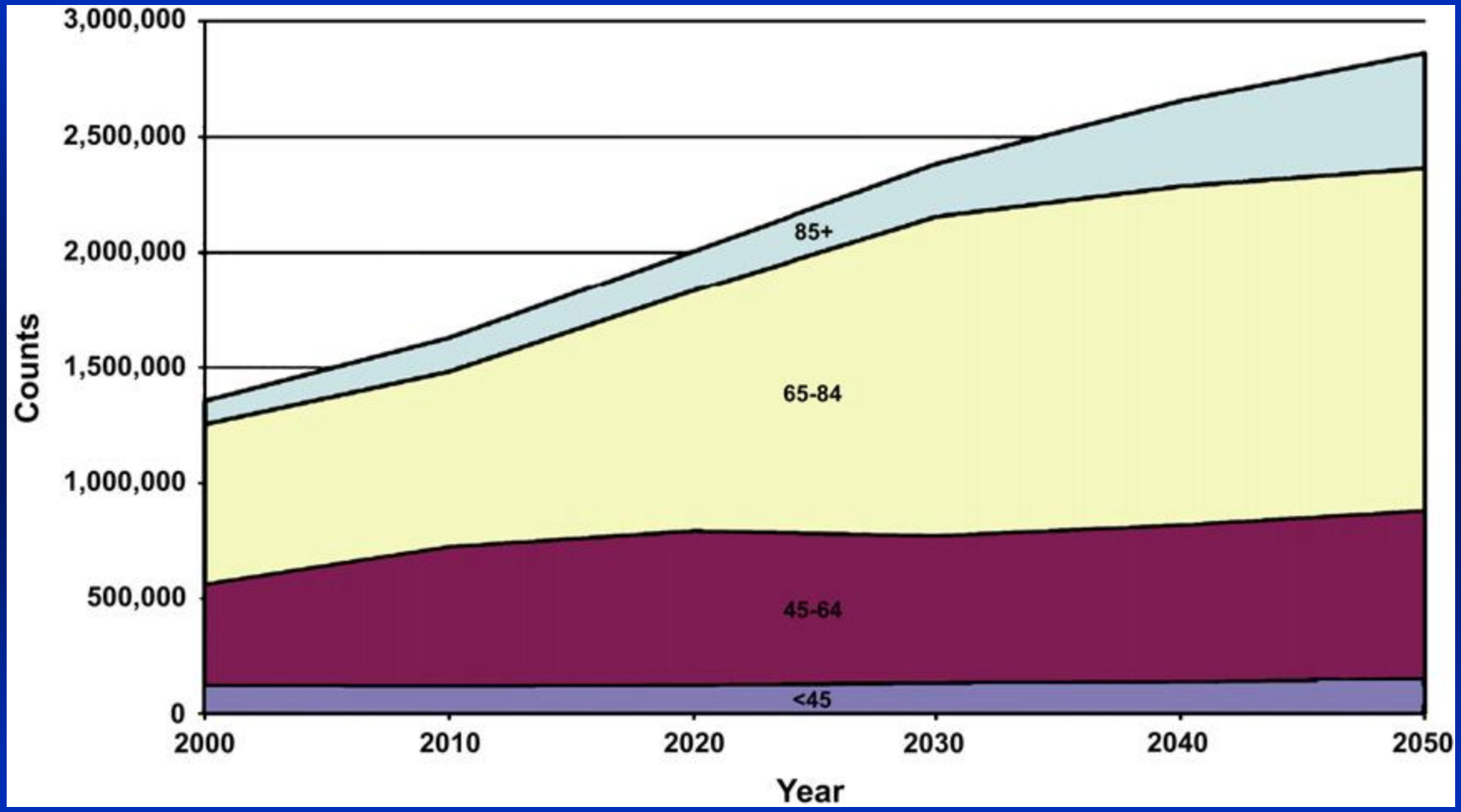
2010 Atlas of End stage Renal Disease in the US. http://www.usrds.org/2010/pdf/v2_00a_intros.pdf

Serious Chronic Illnesses in Older Adults: Some examples

- Cancer as a serious chronic illness
  - Breast cancer death rates decreased 31% between 1989 and 2007
  - Lung cancer (in men) death rate decreasing since 1990
  - Colorectal cancer deaths decreased by 3%/yr between 2003 and 2007

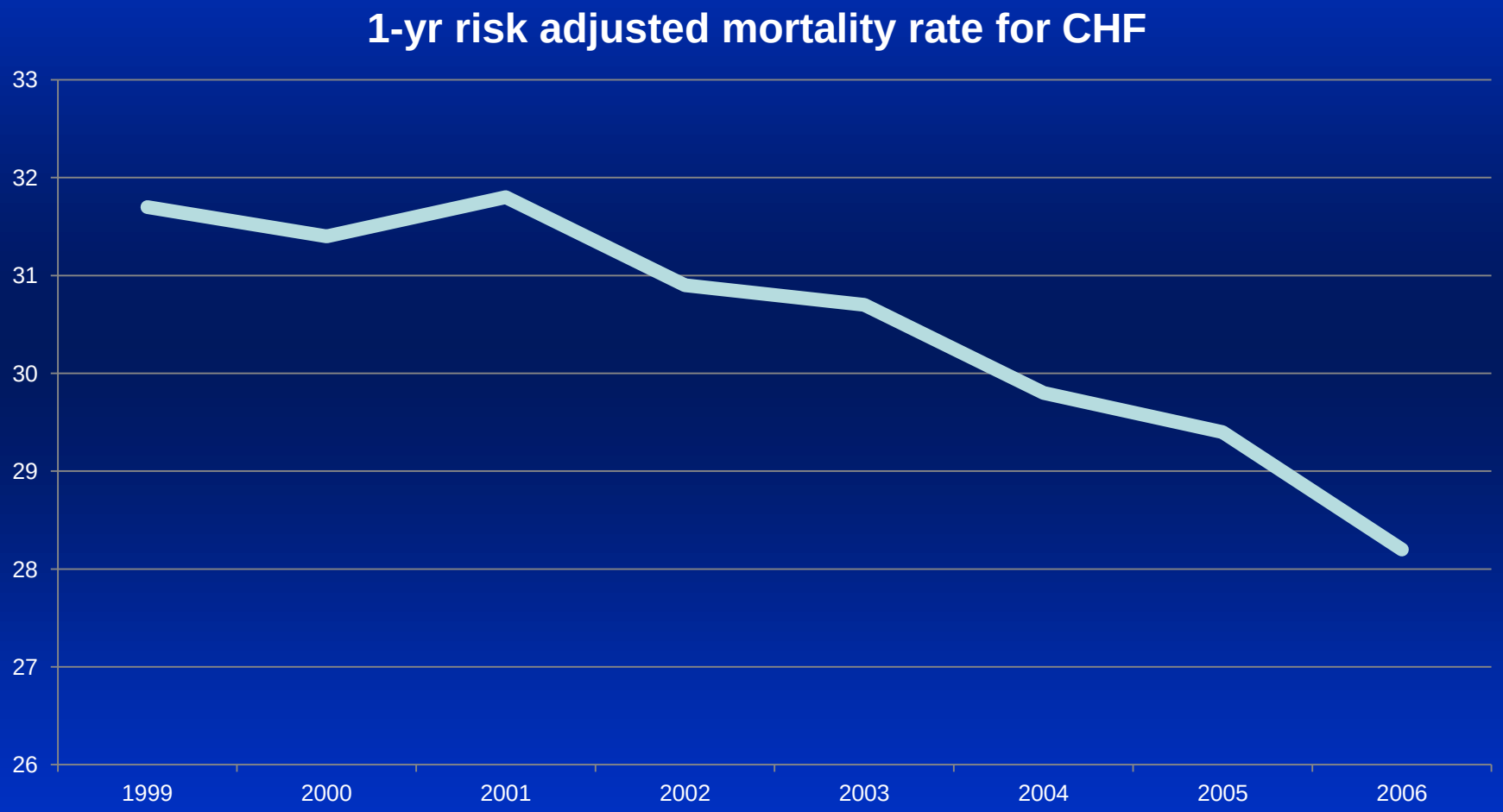
Andre et al. J Clin Oncol 2004;22:3302; ACS Facts and Figures 2010. Jemal et al. *Cancer Epi Biomarkers Prev 2011*

Cancer as a Chronic Serious Illness



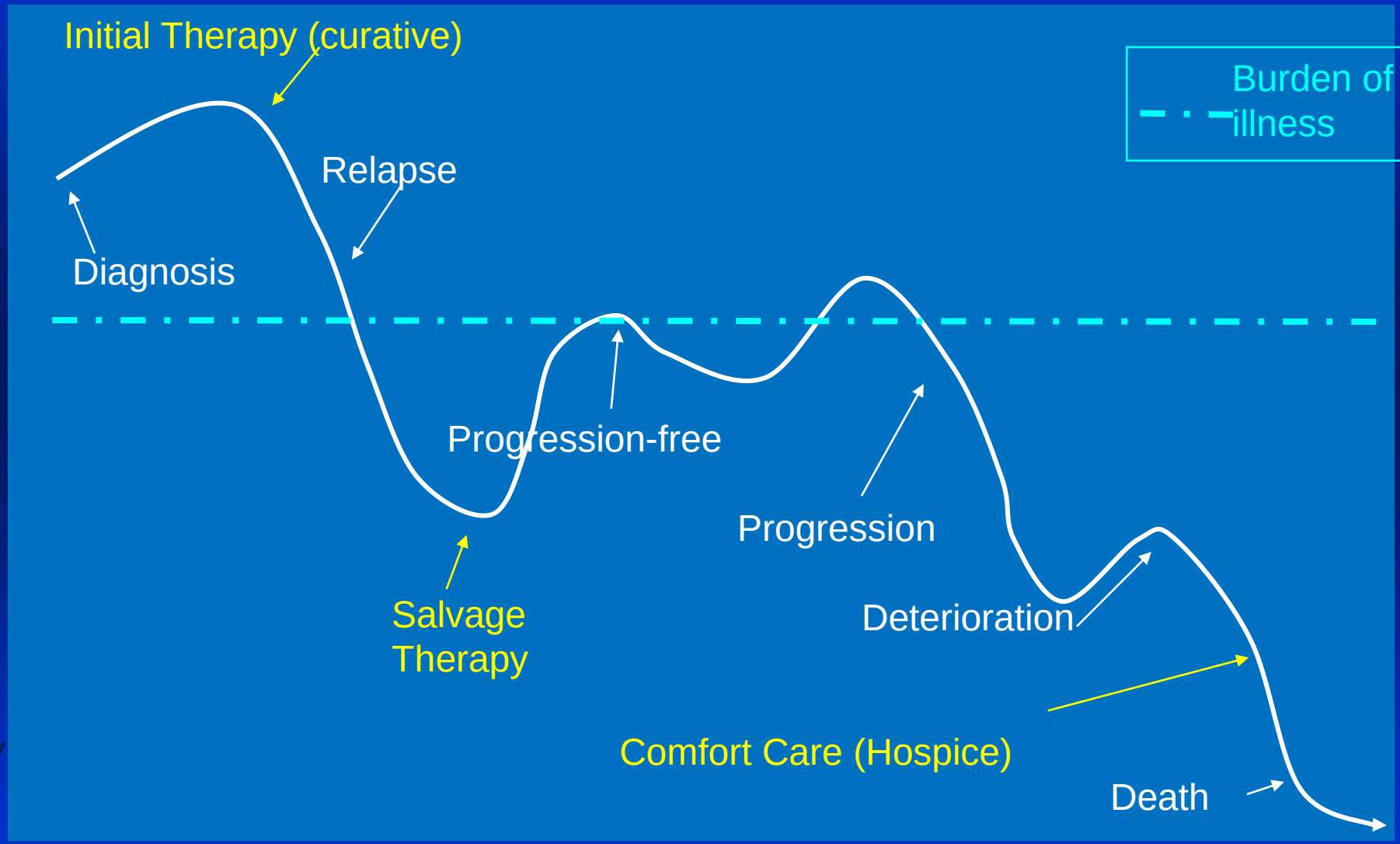
Projected incidence for 2000 to 2050 by age group (<45, 45–64, 65–84, 85+) based on projected census population estimates and delay-adjusted SEER-17 cancer incidence rates. Rowland JH. Hematol Oncol Clin N Am 22 (2008) 181–200

Chronic Serious Illness: CHF



Chen, J. et al. JAMA 2011;306:1669-1678

Disease Trajectory



Illness Burden

The Challenge of Quality and Cost in our new reality

$$\text{Value} = \frac{\text{Quality}}{\text{Cost}}$$

Our Numerator: Quality

- 100,000 deaths/year from medical errors
- Millions harmed by overuse, underuse, and misuse
- Fragmentation
- Evidence Based Medicine <50% of the time
- U.S. ranks 40th in quality worldwide

Quality:
What Do Patients with Serious Illness Want?

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

Singer et al. *JAMA* 1999;281(2):163-168.

Quality:
What Do Patients with Serious Illness Want?

- To have trust and confidence in the doctors looking after you
- Not to be kept alive on life support when little hope for a meaningful recovery
- Information about one's disease communicated to you by your doctor in a honest manner

Heyland DK et al. CMAJ 2006;174:5

Quality:
What Do Patients with Serious Illness Want?

- To complete things and prepare for life's end
- To not be a physical/emotional burden to family
- Upon discharge, have an adequate plan of care
- To have relief of symptoms

Heyland DK et al. CMAJ 2006;174:5

Quality:
What Do Family Caregivers Want?

Study of 475 family members 1-2 years after bereavement:

- Loved one's wishes honored
- Inclusion in decision processes
- Support/assistance at home
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- Honest information
- 24/7 access
- To be listened to
- Privacy
- To be remembered and contacted after the death

Tolle et al. Oregon report card. 1999 www.ohsu.edu/ethics

And What They Get …

Mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents

Not enough …

contact with physician:	78%
emotional support (pt):	51%
information about the dying process:	50%
emotional support (family):	38%
help with pain/dyspnea:	19%

Teno et al. JAMA 2004;291:88-93.

And What They Get …

- 94 family members from 4 ICUs (teaching hospital or VA)
- Family perception of patient's ICU dying and death:
  - Pain under control 47 %
  - Keeping dignity and self-respect 32%
  - Breathing comfortably 3%

Mularski et al. *CHEST. 2005; 128 :280-287*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WAITING ROOM
THANK YOU FOR SUFFERING IN SILENCE

“For people whose diseases will not be cured but instead progress despite aggressive treatments, the very places that are meant to provide the best care can become dystopias of discomfort, false promises, and foreboding.”

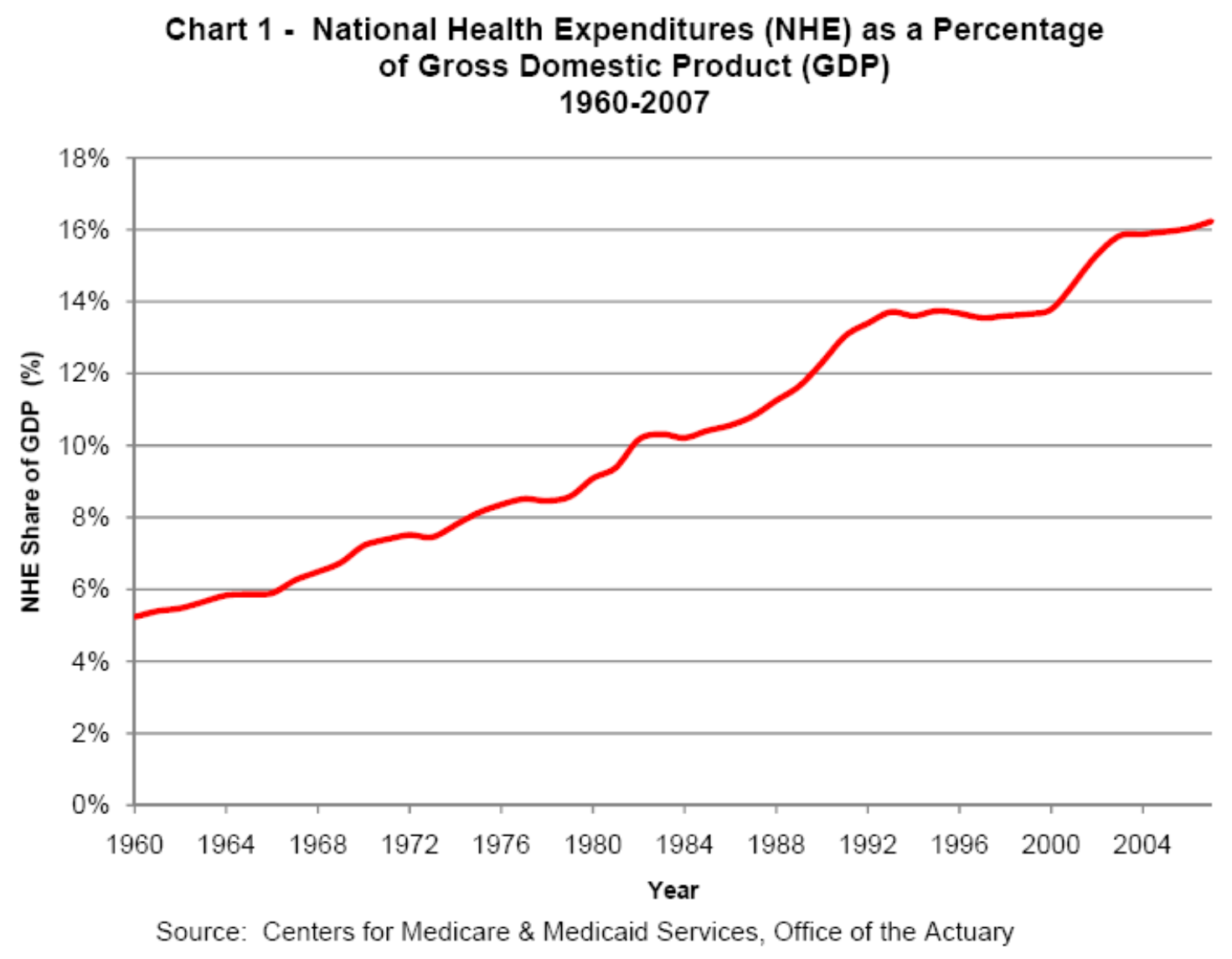
-Ira Byock, *The Best Care*

Our Denominator: Cost

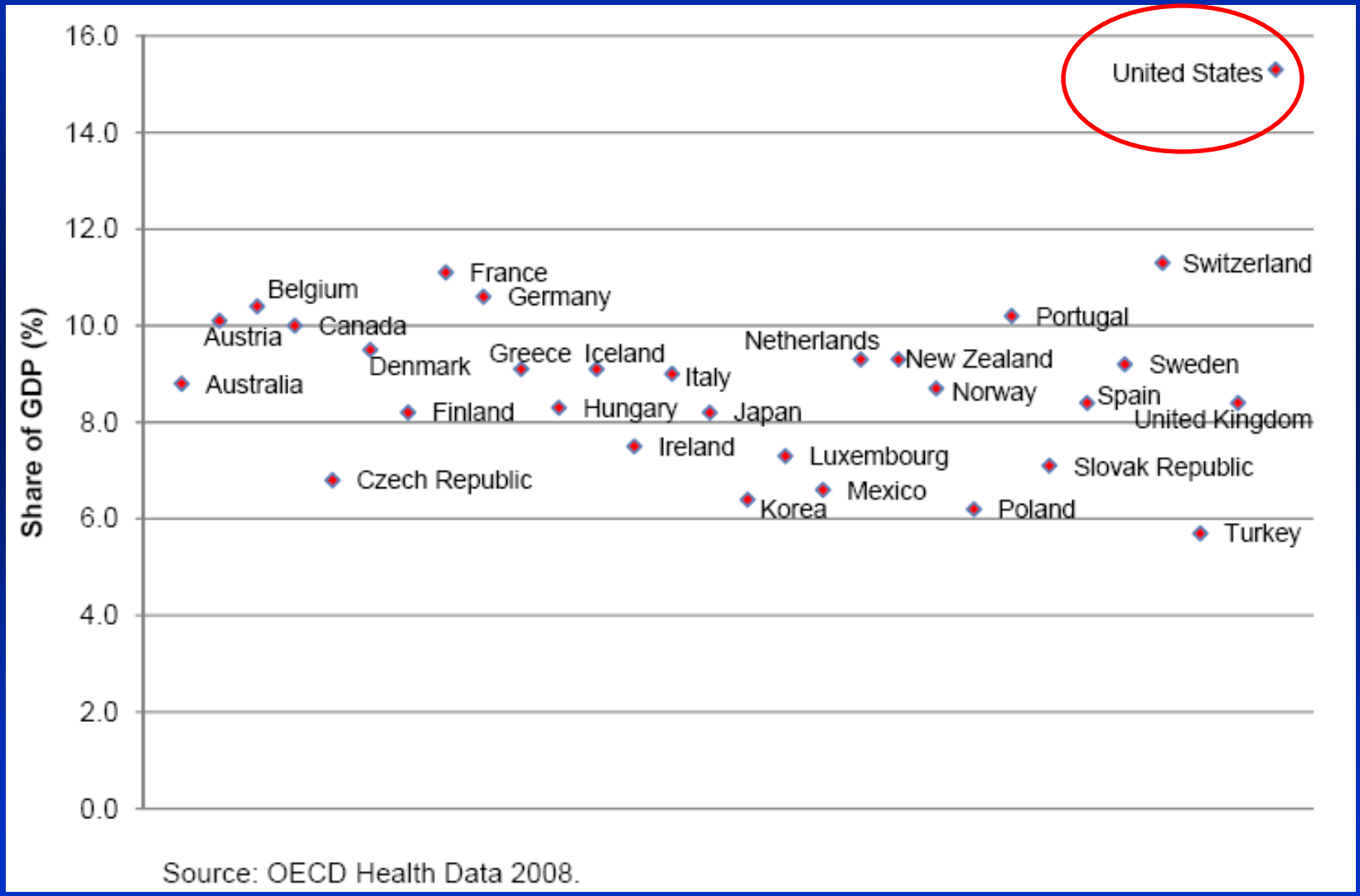
- Health premiums for workers have risen 114 percent in the last decade.
- U.S. spending 17% GDP, >$7,000 per capita/yr
- Despite high spending, 15% of our population has no insurance (18% in AK)
- Lack of health coverage contributes to at least 45,000 preventable deaths/year.

Welper et al. AmJPH 2009, www.cfr.org, Alaska Health Atlas

Cost of Healthcare



Cost of Healthcare



Multimorbidity and Medicare Expenditures

Number of Chronic Conditions	Percent of Beneficiaries 65+	Percent Medicare Expenditures
0	18	1
1	19	4
2	21	11
3	18	18
4	12	21
5	7	18
6	3	13
7+	2	14

63%

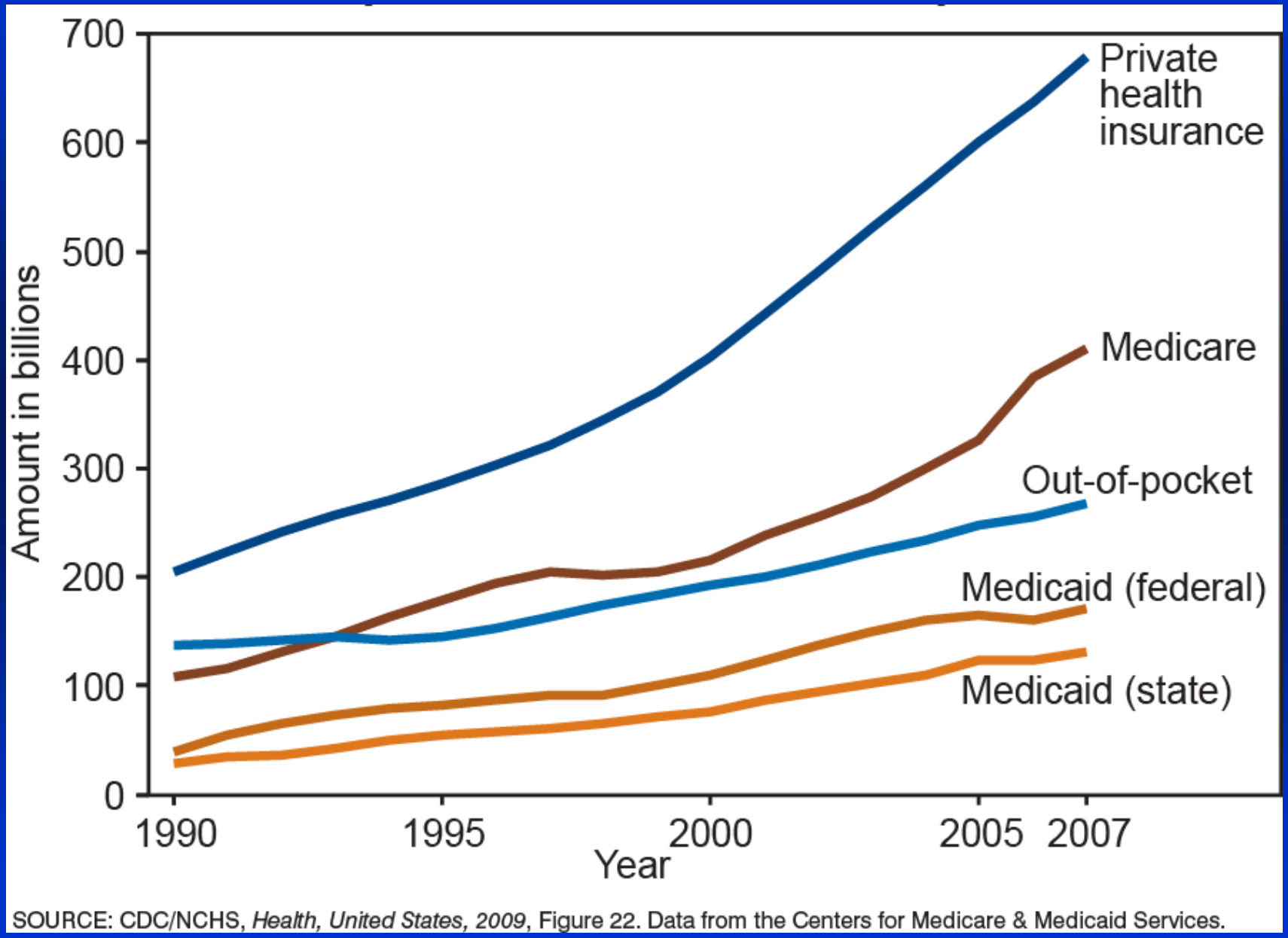
24%

95%

66%

Wolff JL, Starfield B, Anderson G. *Arch Intern Med.* 2002;162:2269-2276

Cost: Personal Expenditures



SOURCE: CDC/NCHS, *Health, United States, 2009*, Figure 22. Data from the Centers for Medicare & Medicaid Services.

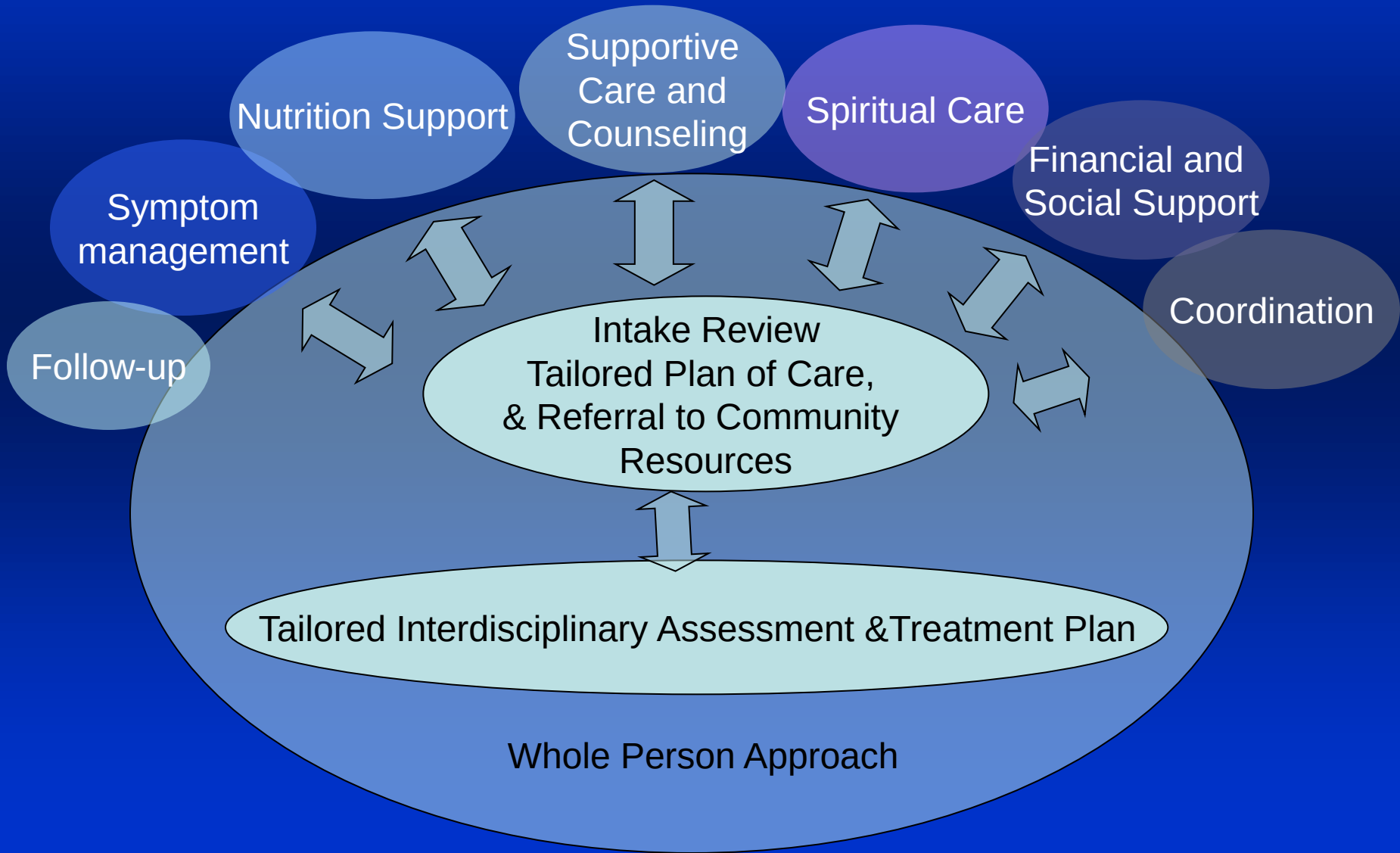
How does palliative care contribute to the value equation in chronic serious illness?

Palliative Care: the Definition

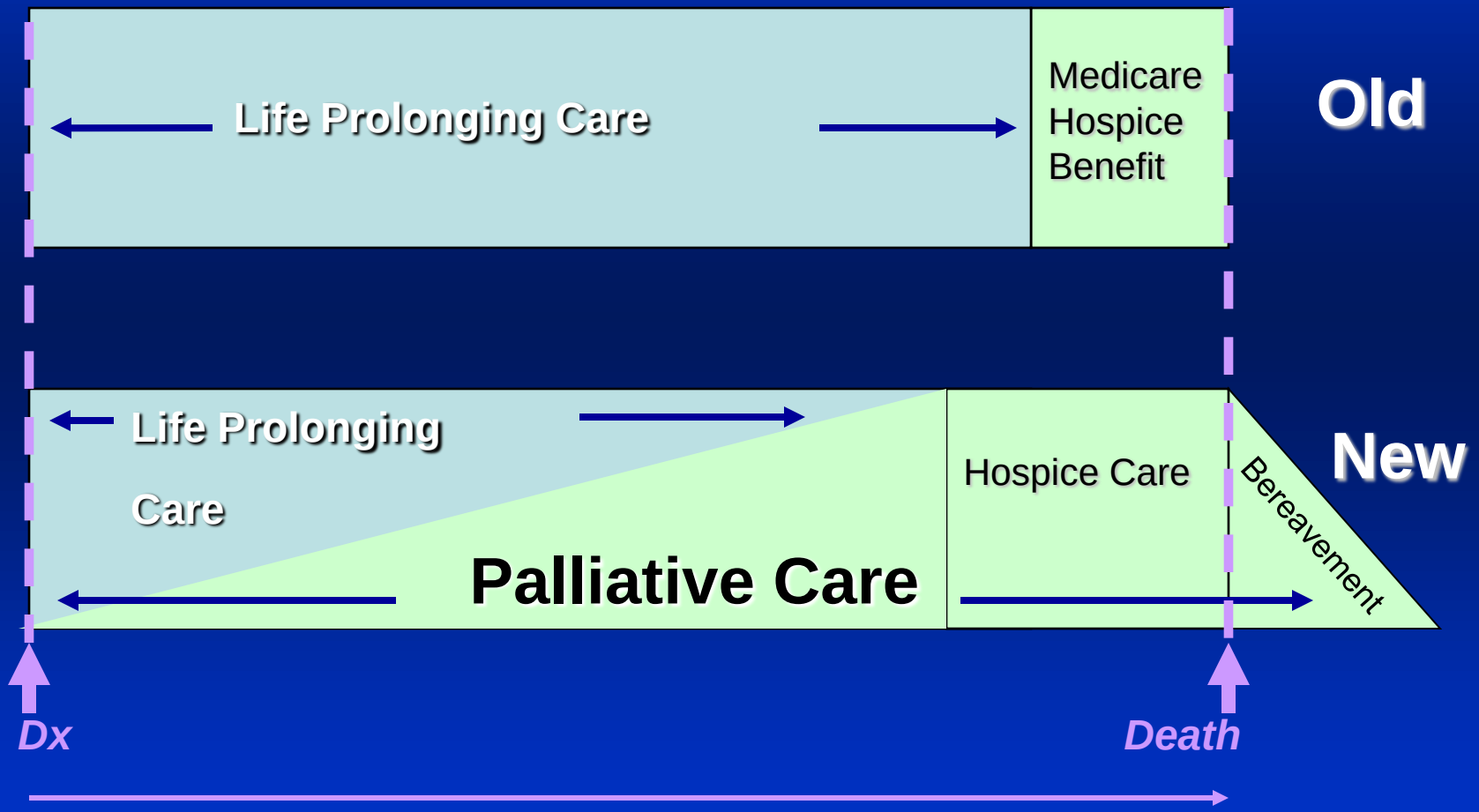
Palliative care means patient and family-centered *care that optimizes quality of life by anticipating,* preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

73 FR 32204, June 5, 2008 Medicare Hospice Conditions of Participation –Final Rule

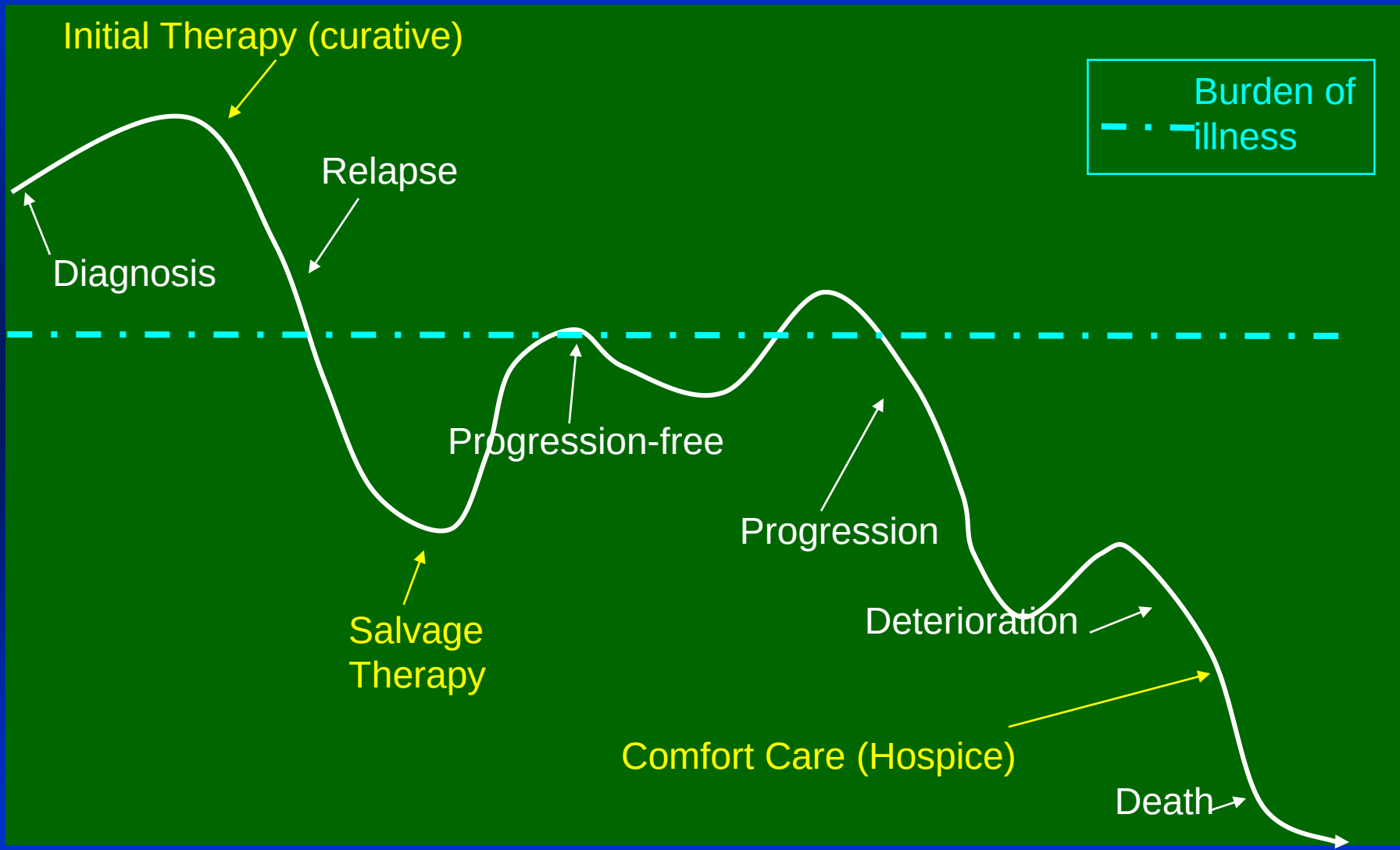
Supportive Care = Team Care



Conceptual Shift for Palliative Care



Palliative Care- Dynamic, Not Linear



Illness Burden

Palliative Care and Patient/Caregiver Satisfaction

Mortality follow back survey palliative care vs. usual care (N=524 family survivors)

Overall satisfaction markedly superior in palliative care group, p<.001; Palliative care superior for:

- emotional/spiritual support
- information/communication
- care at time of death
- access to services in community
- pain
- well-being/dignity
- care + setting concordant with patient preference
- PTSD symptoms

Casarett et al. J Am Geriatr Soc 2008; *Jordhay et al Lancet 2000; Higginson et al, JPSM, 2003; Finlay et al, Ann Oncol 2002; Higginson et al, JPSM 2002.*

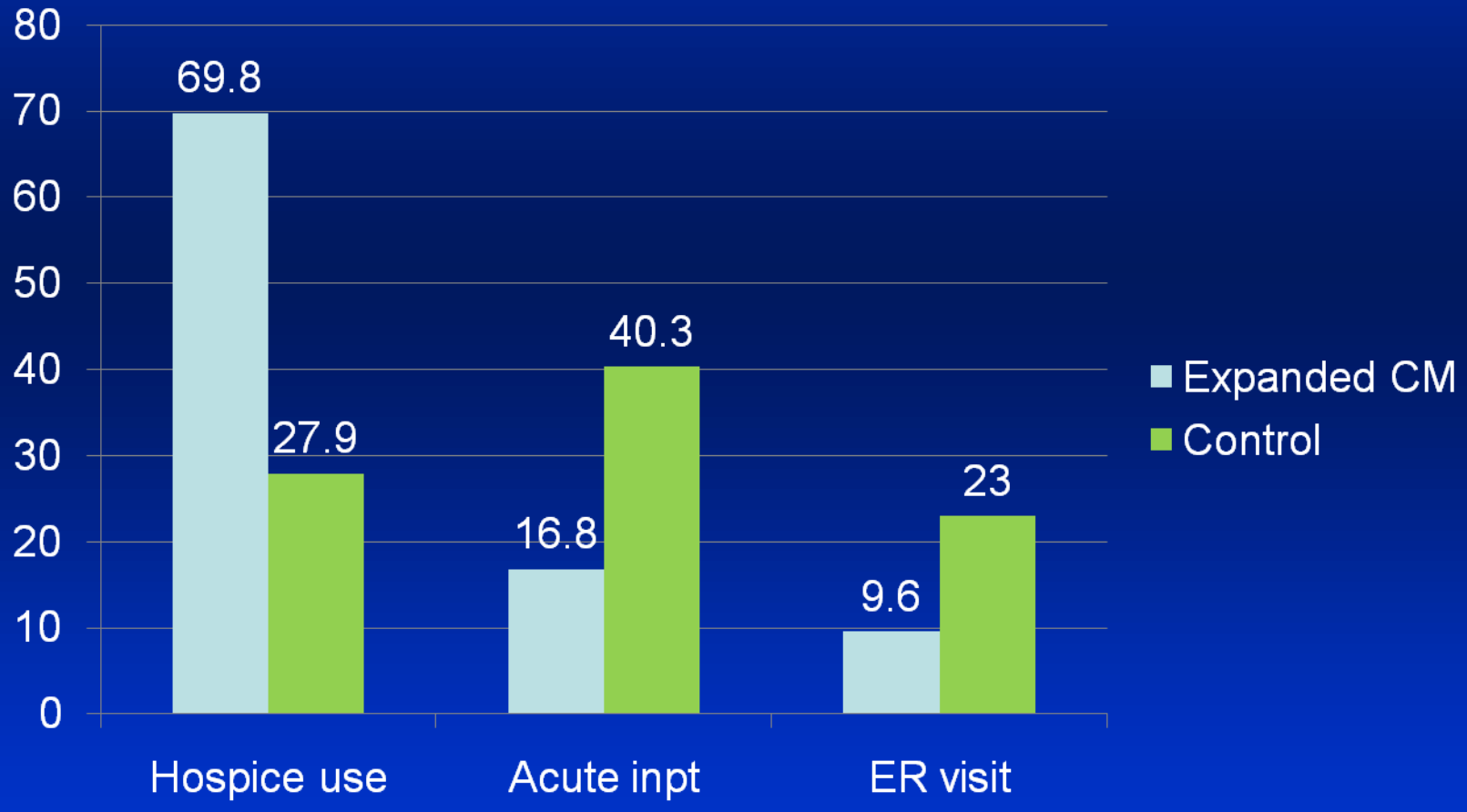
Palliative Care, Quality and Costs

- In a prospective multicenter study of 332 seriously ill cancer patients, recall of occurrence of a prognostic/goals conversation was associated with:
  - Better quality of dying and death
  - Lower risk of complicated grief + bereavement
  - Lower costs of care
  - Less ‘aggressive’care

Zhang et al. Arch Int Med 2009;169:480-8.
Wright et al. JAMA 2008;300:1665-73.

Palliative Care and Healthcare Utilization

"Expanded" hospice/CM services to 387 Aetna beneficiaries with advanced illness



Spettell CM et al. JPM 2009; 12: 827-832

Palliative care and survival

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

ABSTRACT

BACKGROUND

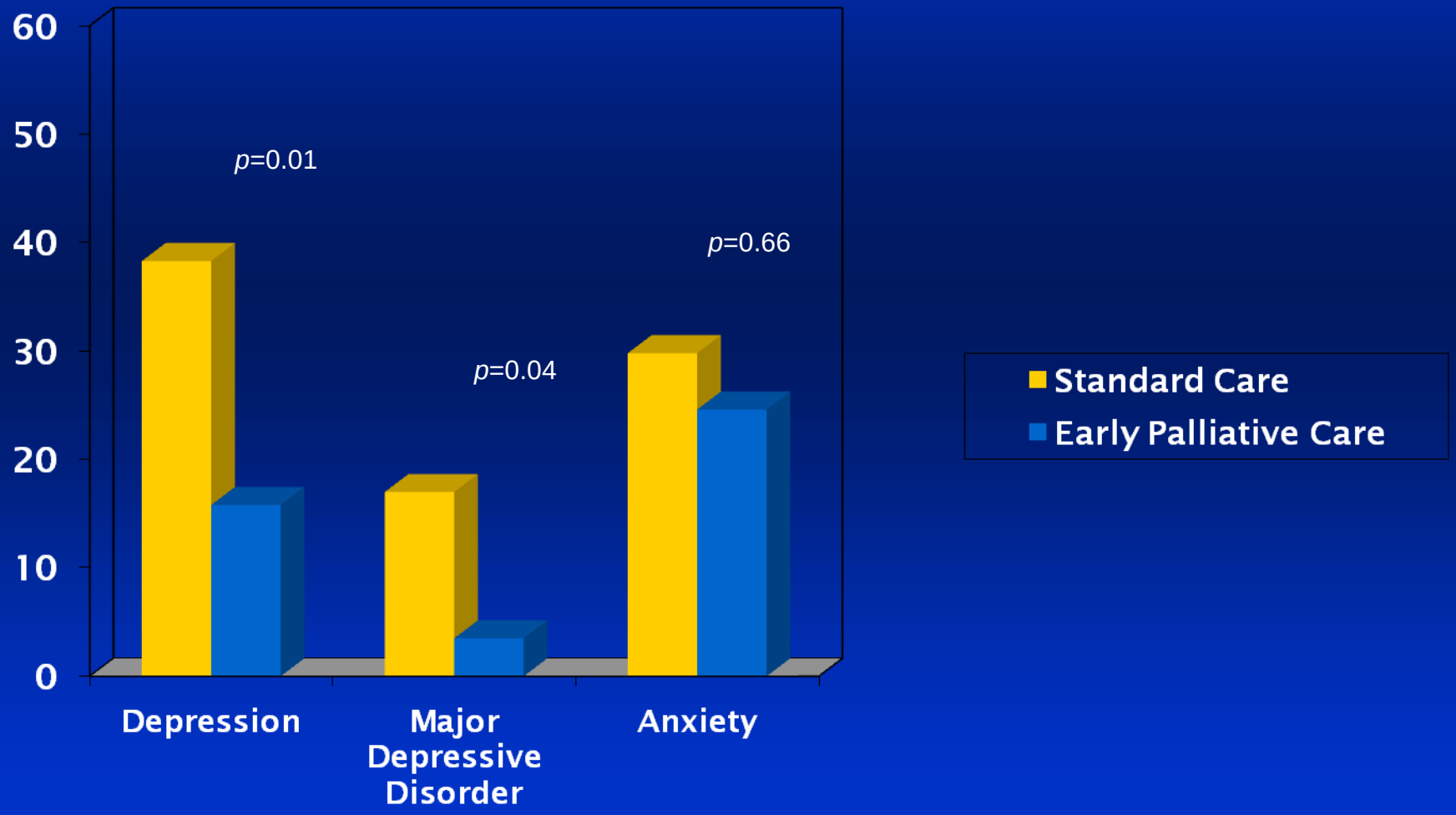
Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS

We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer

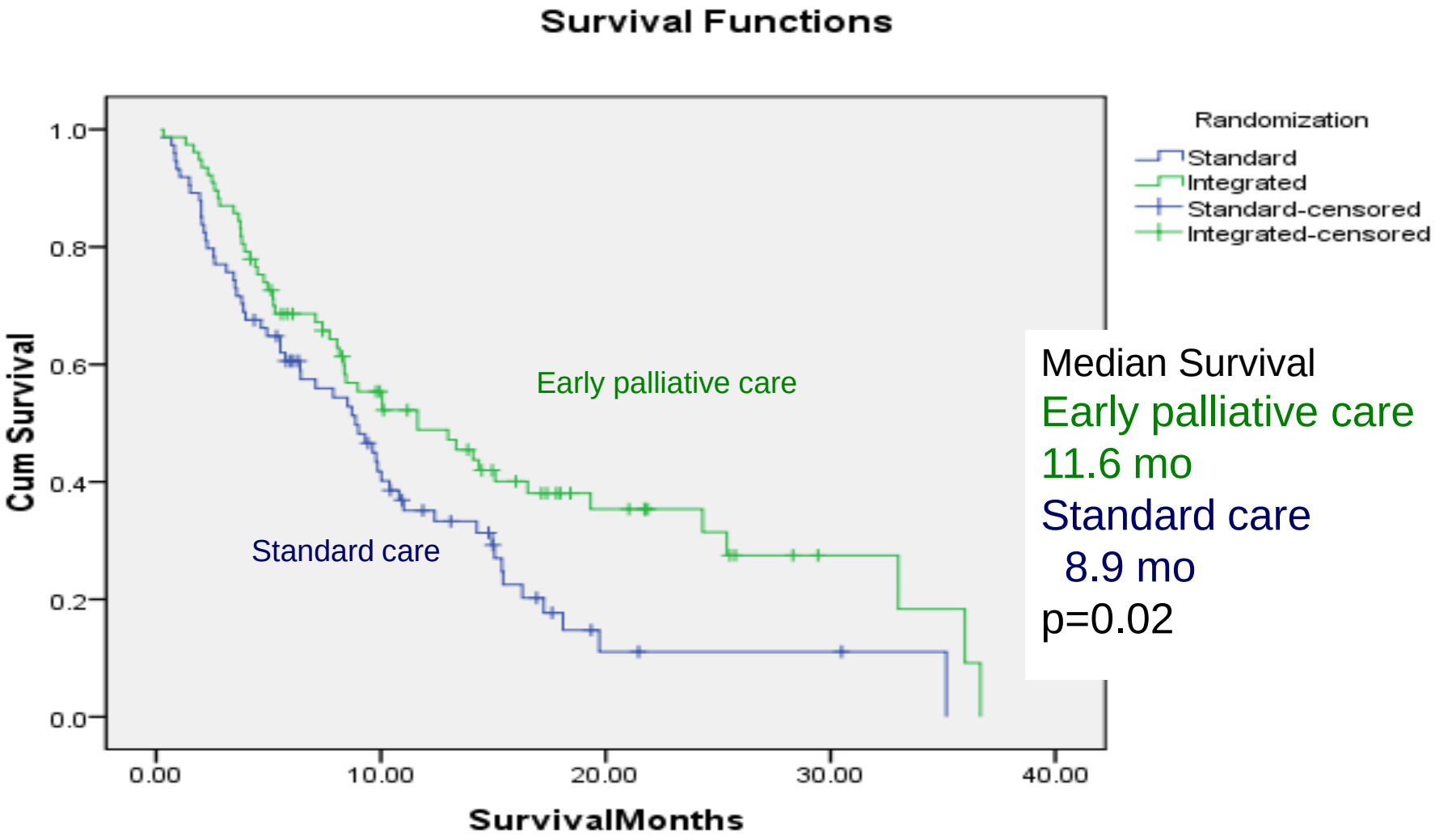
Temel J et al. NEJM 2010; 19 :733-742.

Effect of Early PC on 12-week Psychological Distress



Temel J et al. NEJM 2010; 19 :733-742.

Survival



Median Survival

Early palliative care

11.6 mo

Standard care

8.9 mo

p=0.02

Temel J et al. NEJM 2010; 19 :733-742.

How might palliative care support patient centered care across the continuum?

How might palliative care support patient centered care across the continuum?

- Provider focus- education and specialty access
- System focus- triggers/care transitions
- Integration/technology focus- telehealth

Education in basic palliative care skills

- Advance care planning
  - What are the goals of care?
  - Are treatment options matched to informed patient-centered goals?
  - Has the patient participated in an advance care planning process?
  - Has the patient completed an advance care planning document?

Weissman DE Arch Int Med. 1997;157:733-7.

Education in basic palliative care skills

- Communication skills (e.g. giving bad news; empathic opportunities)
  - Does the patient/family understand the current illness, prognostic trajectory and treatment options?
  - Are there significant social/spiritual concerns affecting daily life?

Weissman DE Arch Int Med. 1997;157:733-7.

Education in basic palliative care skills

- Symptom assessment/management
  - Are there distressing physical or psychological symptoms?
  - Is there a management plan to address them?

Weissman DE Arch Int Med. 1997;157:733-7.

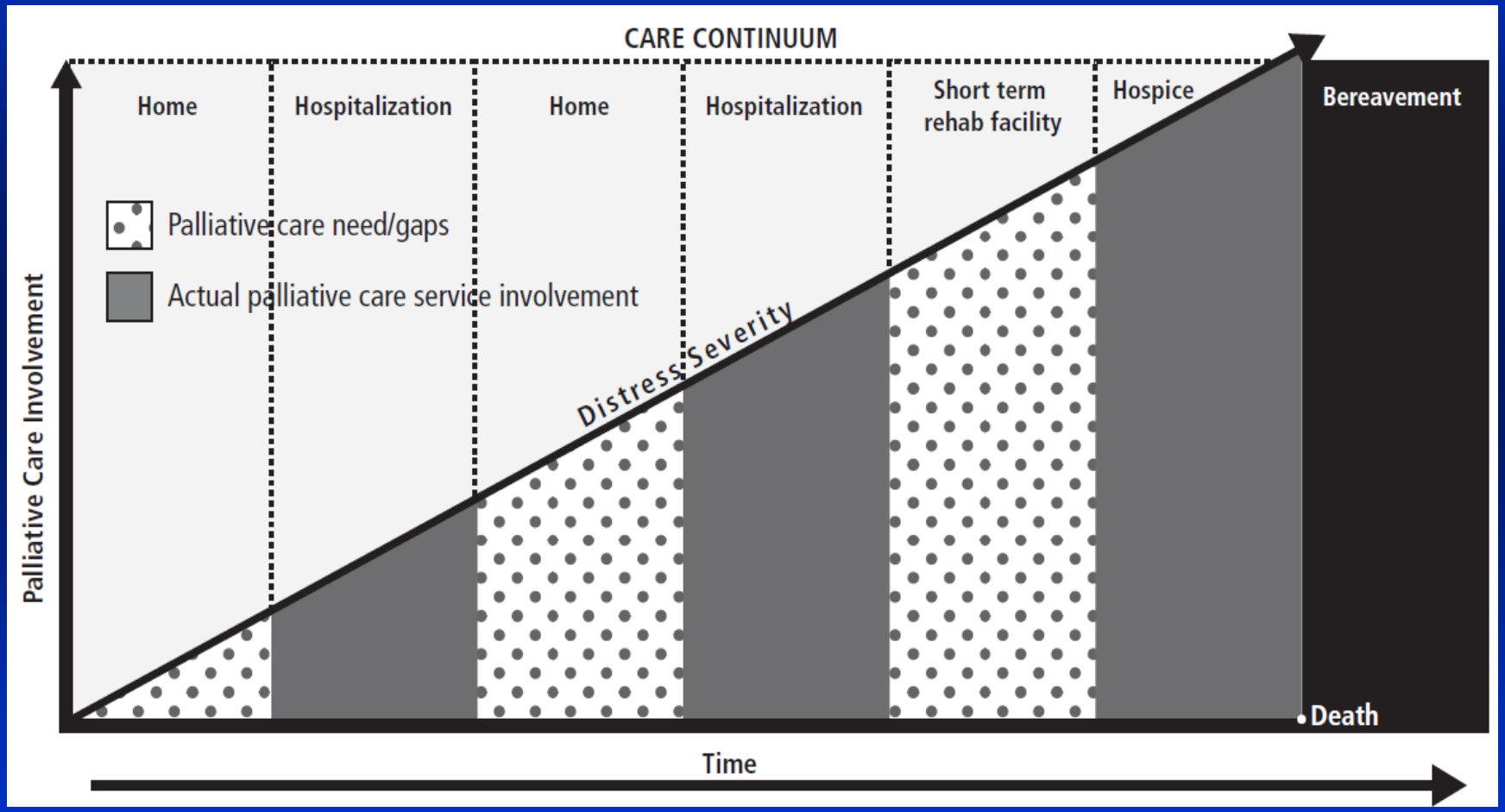
Specialized Complex Illness Care

Comanagement and Palliative Care

concurrent care

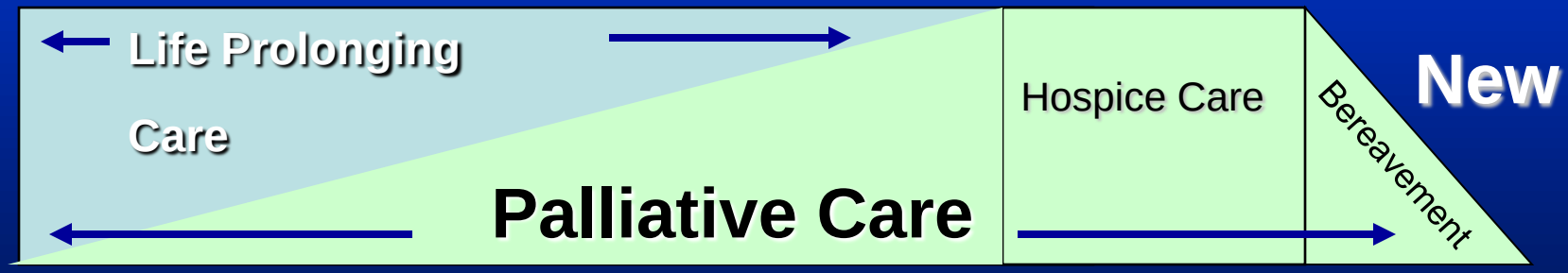
1. *operating or occurring at the same time*
2. *running parallel*
3. *acting in conjunction*
4. *exercised over the same matter or area by two different authorities*

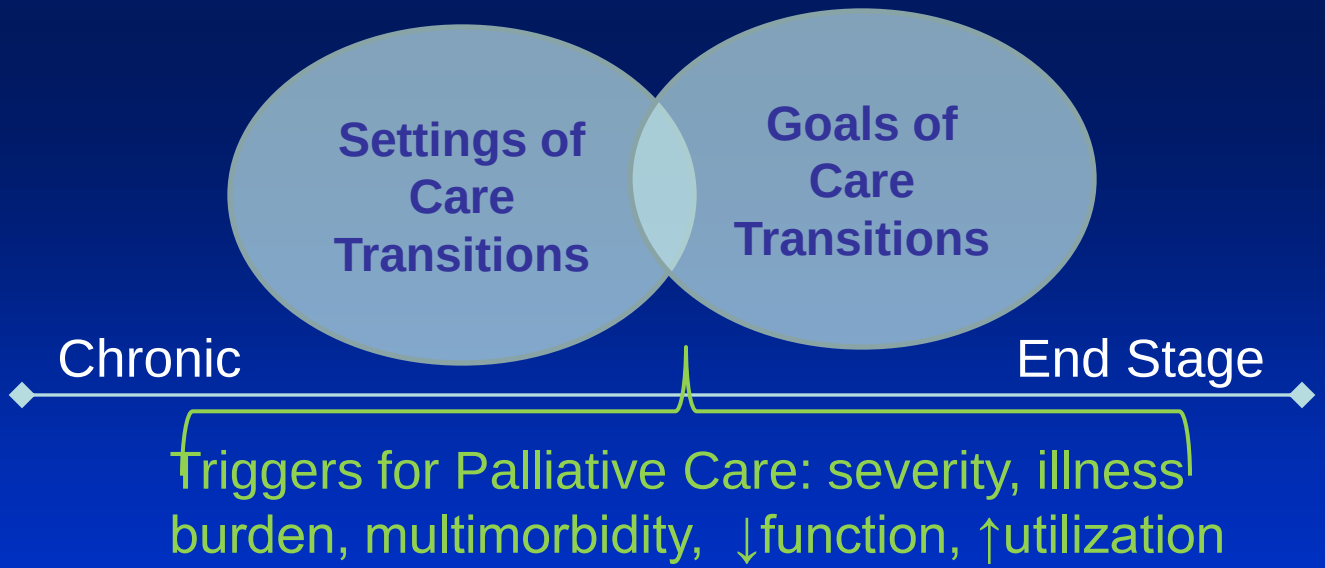
System Focus: Care gaps in current palliative care delivery models



Kamal et al. Journal of Pain and Symptom Management. 2012, In Press

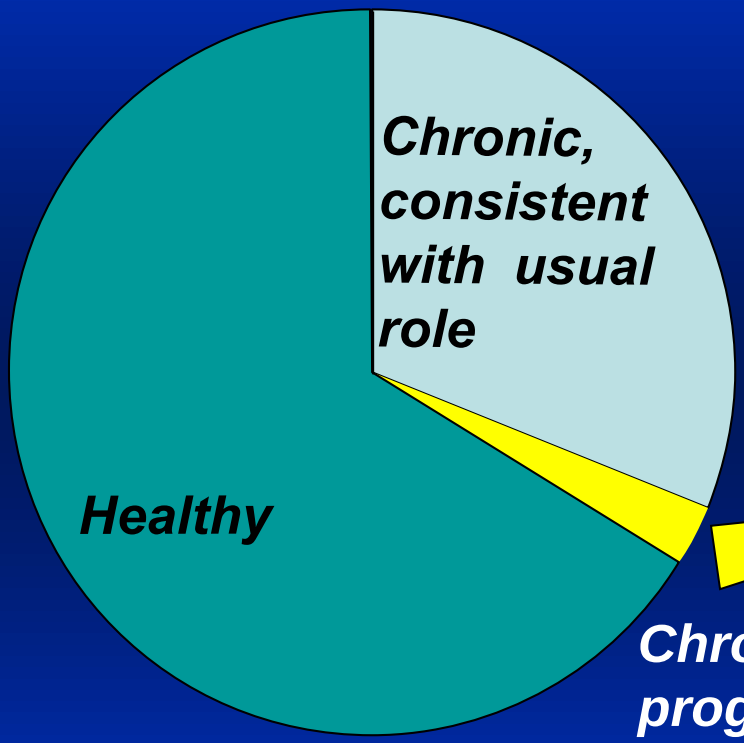
The Palliative Care Continuum





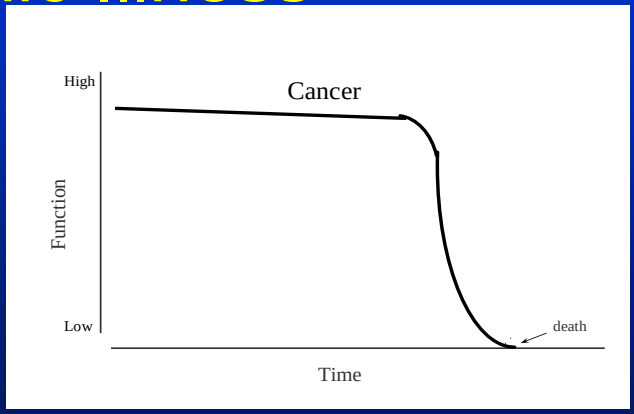
Adapted from/courtesy of J Kutner

Health Status in the Population and Among Persons with Eventually Fatal Chronic Illness



Chronic, progressive, eventually fatal illness

A



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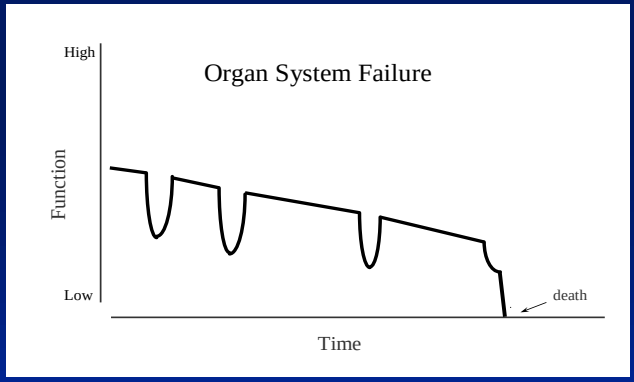

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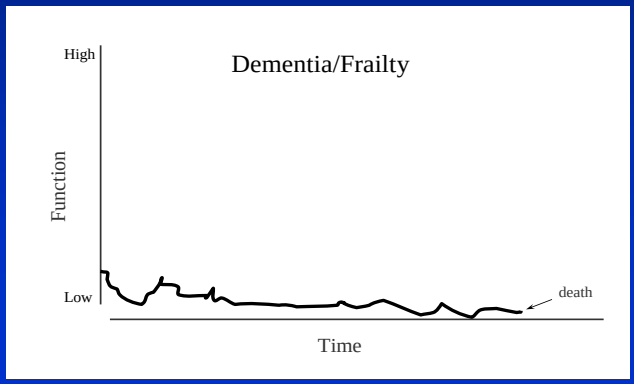


Triggers for Specialized Palliative Care in the Hospital:

- You would not be surprised if the patient died within 12 months or to adulthood
- Difficult to control physical or psychological symptoms
- ICU stay ≥ 7 days
- Lack of clarity/documentation re Goals of Care
- Disagreements or uncertainty concerning major med rx decisions

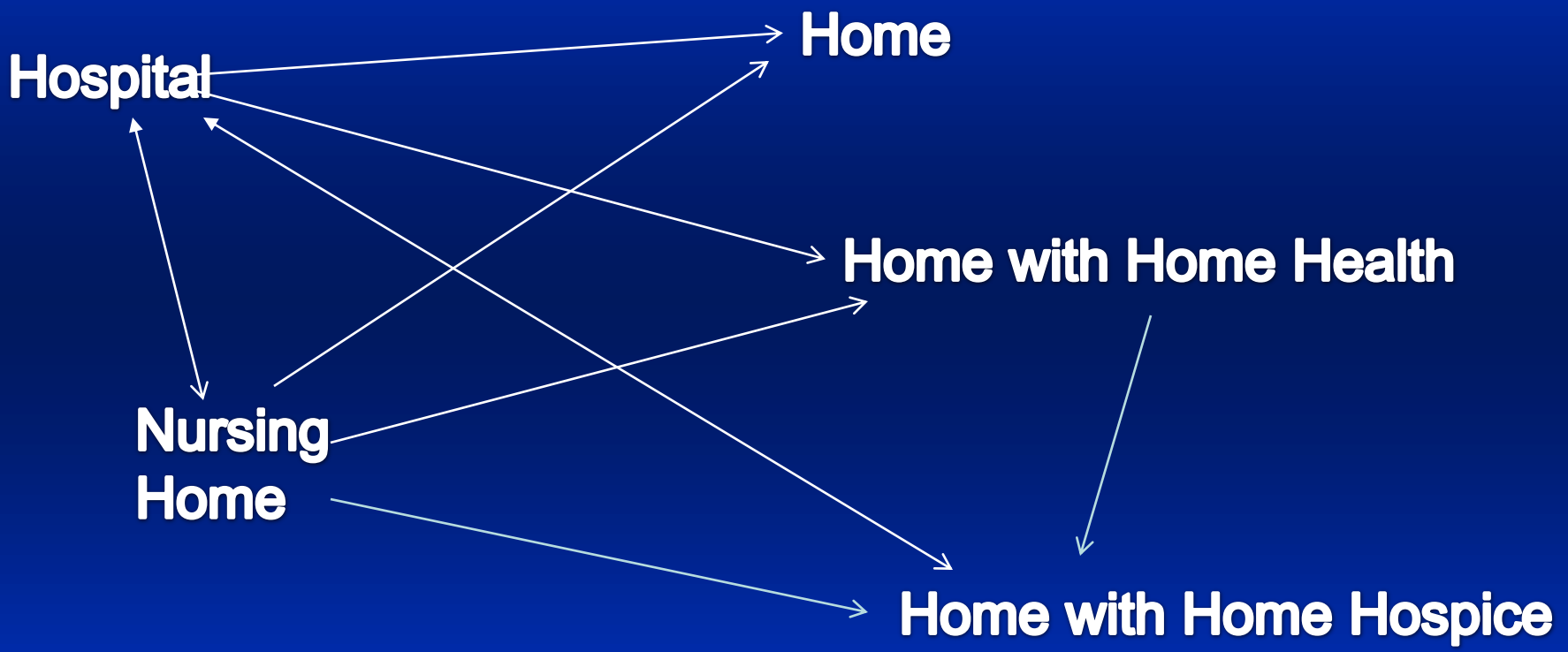
Weissman & Meier JPM 2011; 14:1-7

Triggers for Specialized Palliative Care in any setting:

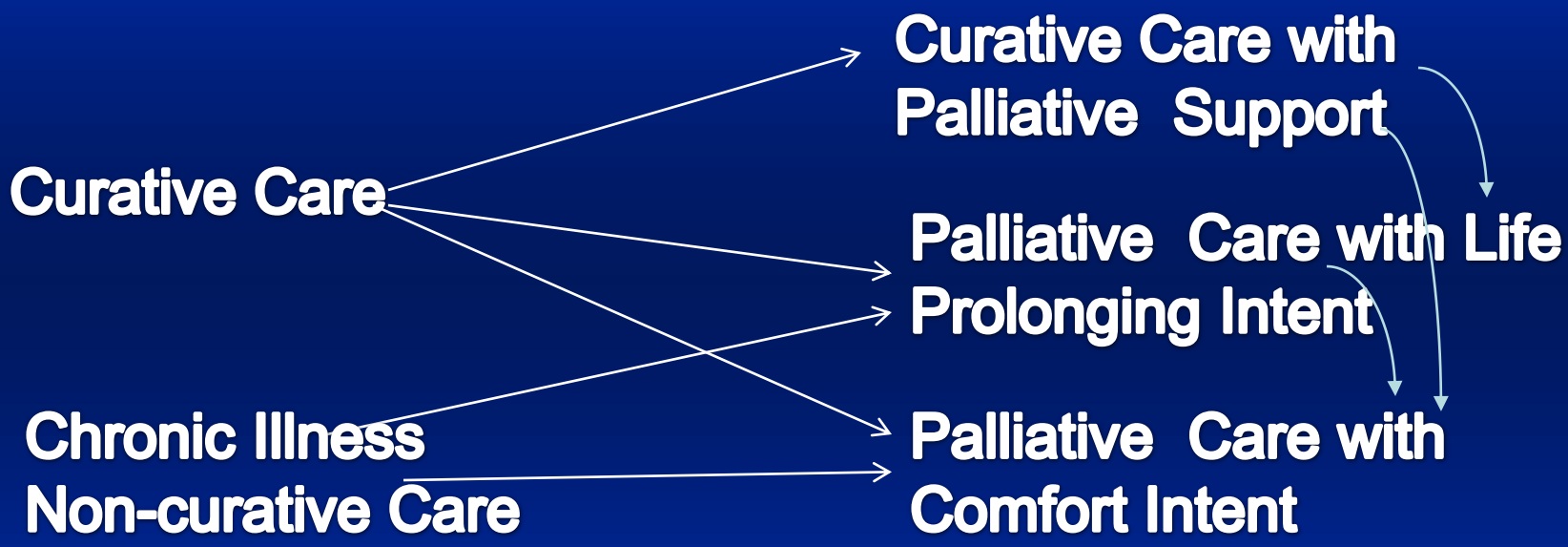
- Awaiting or deemed ineligible for solid-organ transplantation
- Pt/family/surrogate physical emotional, spiritual or relational distress
- Pt/family/surrogate request for palliative care/hospice services
- Pt/medical team is considering/seeking counsel for feeding tube placement, tracheostomy, dialysis, ethics, LVAD, LTAC

Adapted from Weissman & Meier JPM 2011; 14:1-7

Types of Care Transitions: Settings



Types of Care Transitions: Goals



Care Transition: A High Risk Event

- Approximately 20% of recently discharged patients experience adverse events, often precipitated by ineffective communication

- Almost 12% report new or worsening symptoms within 3 to 5 days of leaving the hospital

- One-quarter of Medicare beneficiaries post hospitalization experienced a complicated care transition within the first 30 days post-discharge

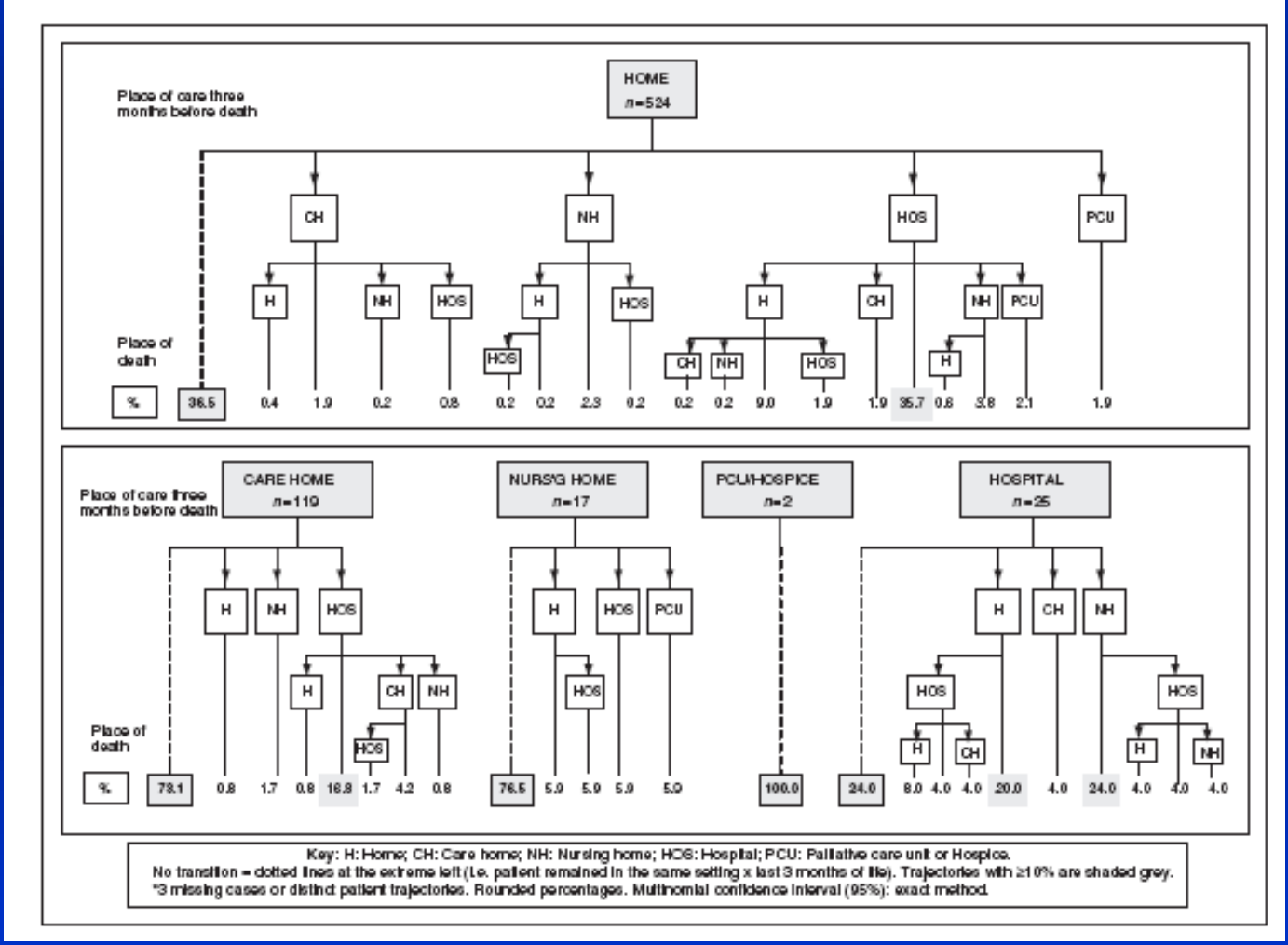
Jencks et al. N Engl J Med 2009;360:1418-28.

Care Transitions in Advanced Illness

- Mortality “follow-back” study of 690 pts in the Netherlands
- Died 'totally expectedly and non-suddenly‘
- 709 transitions in the last 3 months, which involved a hospital two times out of three, and covered 43 distinct care trajectories
- 46% experienced one or more transitions in their last month of life.

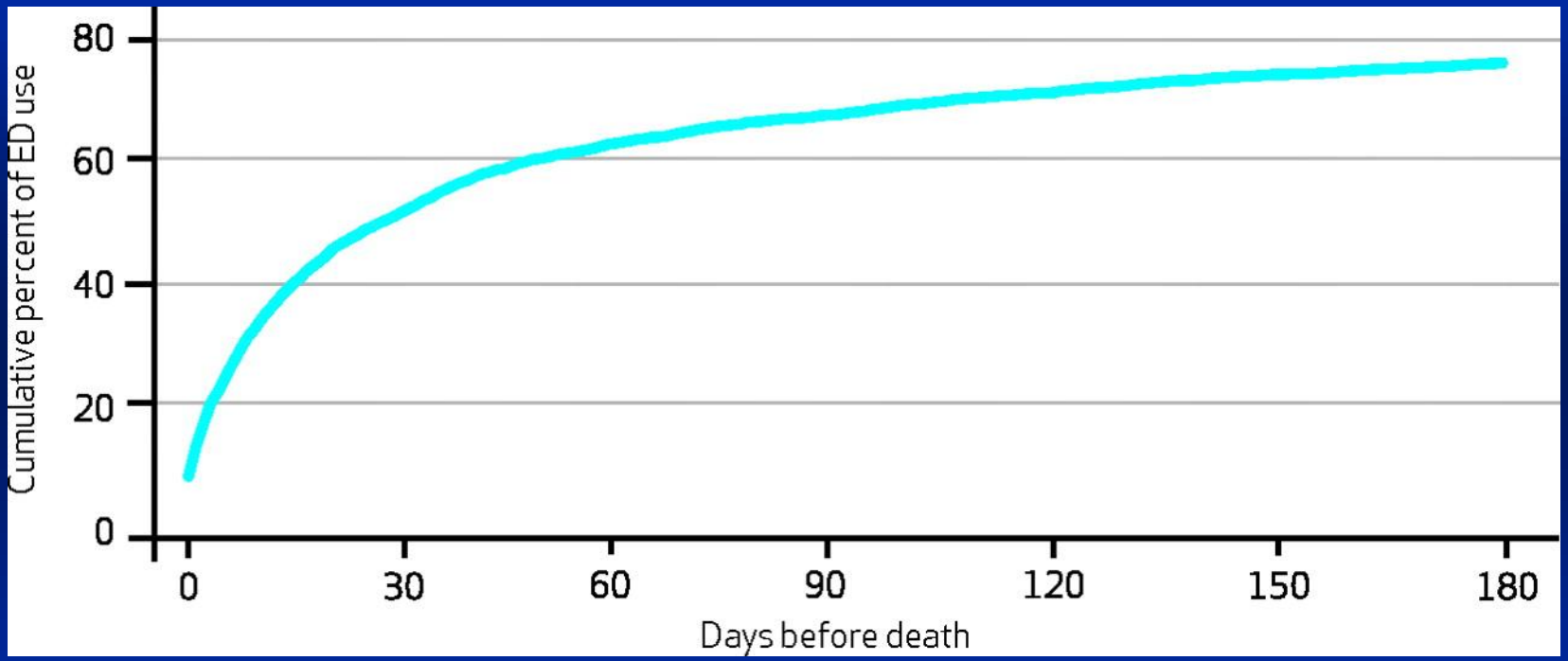
Abarshi et al. Palliat Med. 2010 Mar;24(2):166-74

Care Transitions: Last 3 months of Life



Abarshi et al. Palliat Med. 2010 Mar;24(2):166-74

Cumulative Incidence Of Emergency Department (ED) Visits During The Last Six Months Of Life For Decedents In The Health And Retirement Study, 1992–2006.



Of the 4,158 decedents, 9 percent visited the emergency department on the last day of life, 51 percent had visited it within thirty days before death, and 75 percent had visited within 180 days before death.

Smith A K et al. Health Aff 2012;31:1277-1285

HealthAffairs

Characteristics Associated with ER use in the last month of life

- African American or Latino ethnicity
- Moderate or severe pain were 4 percent
- Patients who did not enroll in hospice early
- ADL dependency
- Lower levels of cognitive impairment

Smith A K et al. Health Aff 2012;31:1277-1285

Risk Factors for Care Transitions (CT) in Advanced Illness

- RF for CT last 30 days of life:
  - Male gender
  - Multi-morbidities,
  - Absence of GP awareness of a patient's wish for place of death
- RF for terminal hospitalization for > or = 7 days:
  - age of < or = 85 years
  - having an infection
  - absence of a palliative-centered treatment goal

Abarshi et al. Palliat Med. 2010 Mar;24(2):166-74

Improving Care Transitions: Information Transfer between Providers

- Roles, lines of communication
- Treatment options, patient preferences, and treatment plans (e.g. POLST/MOLST)
- Communication/consensus building regarding relative benefit/burden of specific interventions (e.g. coumadin, statins, acetylcholinesterase inhibitors)

Improving Care Transitions: Patient/Caregiver Information

- What to expect
- What to do
- Who to call

Improving Care Transitions: Self Management Support

- Medications
- Follow-up
- Knowledge by pt/caregiver of red flags
  - Escalation of pain
  - Altered mental status
  - Fever
- Knowledge of “who to call”

Improving CT: Empowerment to Assert Preferences

- Anticipation and management of “what ifs”
- Understanding of what different programs and treatment settings do and don’t provide
- Access to a healthcare provider and decision maker

Care Transitions and Palliative Care

- Transition 1: would my patient benefit from supportive and palliative care to address illness burden?
- Transition 2: would my patient benefit from supportive and palliative care to manage their advanced illness?
- Transition 3: Is my patient reaching the last days of life?

Boyd & Murray. BMJ 2010; 341:c4863

Palliative Care, IT, and Telehealth

- Monitoring
  - Synchronous
  - Asynchronous
- Video-conversing
- Diagnosing
- Treating

A story of a good death…

Comfort, community, dignity…

Summary

- Our new reality of chronic serious illness is stressing our healthcare system
- Integration of palliative care into the continuum of care can positively impact outcomes
- There is an ocean of possibilities for using palliative care to improve the healthcare value equation